Palliative care drug boxes: facilitating safe & effective symptom management for home end of life care for children and young people

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End of life care in children different to adults for several reasons
- Death in childhood is relatively rare
- Home clearly demonstrated as preferred place for end of life care for children and young families
  
- Majority of children with cancer die at home if that is their choice.
- GP’s and other primary care professionals will have limited experience
- Specialist palliative care services often cover wide geographical area

In adult palliative care anticipatory prescribing for the management of symptoms at home is recommended
(Matthews et al 2006, GSF 2006, End if Life Care Strategy 2008)
- The Liverpool Care of the Dying Pathway
- Gold Standards Framework
- Preferred place of care
Background

- Specific remit of the Macmillan Outreach and Specialist Palliative Care Team to facilitate end of life care in the place of choice.
- Evaluation of palliative care practice in 1997 demonstrated several key issues for symptom management in home based end of life care.
- Home increasingly the place of choice of care

- Symptom management was ad hoc
- Frequent requirement for rapid symptom management
  - New drugs
  - Change of route
- Access to palliative care drugs and equipment out of hours difficult.
- Large geographical area covered by team
Project development

- Need identified to provide effective access to palliative care drugs and equipment to facilitate rapid and effective symptom management at home
- Joint initiative between Macmillan team and Oncology pharmacist
- 16 months to develop
- Legal issues of dispensing and carrying drugs addressed
- Combined release prescription designed for all drugs including Diamorphine.
- Boxes contained a sufficient supply for 72 hours of most commonly used palliative care drugs
- Ambulatory pump and equipment for IV or SC infusion also provided
- Specific documentation for administration documentation
- Original costs of drugs in box £60.64 (4 boxes £14)
- Boxes prescribed a few days in advance
  - Dispensed by the hospital pharmacist
  - Transported to the patients home by the palliative care nurse specialist
- First box dispensed in 1998
ROYAL LIVERPOOL CHILDREN'S NHS TRUST
ONCOLOGY PALLIATIVE HOME CARE BOX PRESCRIPTION
(Prescription to be completed in Doctors own handwriting)

Please supply for: Patient's Name: ................. Weight (Kg): ................. D.O.B.: .................
Address: .......................................................... Unit Number: .................

One Oncology palliative home care box, containing the drugs and quantities detailed below. This supply is made on the understanding that a clear direction of the dose to be administered is given by a doctor responsible for the patient's care (e.g. Oncology team Specialist Registrar/Consultant at the RLCH or patients General Practitioner), on the RLCH Community Palliative Care Drug Administration Record.

<table>
<thead>
<tr>
<th>DRUG</th>
<th>STRENGTH</th>
<th>QUANTITY</th>
<th>DIRECTIONS</th>
<th>PACK DISP.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclazine</td>
<td>50 mg/ml</td>
<td>10</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Chlorpheniramine</td>
<td>10 mg/ml</td>
<td>5</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Dexamethasone</td>
<td>4 mg/ml</td>
<td>5</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Diazepam (IV)</td>
<td>10 mg/2 ml</td>
<td>2</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Diazepam (Rectal Suppository)</td>
<td>5 mg</td>
<td>5</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Haloperidol</td>
<td>5 mg/ml</td>
<td>5</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Hydrocortisone Sodium Succinate</td>
<td>120 mg</td>
<td>2</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Hyoscine Hydrobromide</td>
<td>400 mcg/ml</td>
<td>5</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Hyoscine Hydrobromide Priapism</td>
<td>1 mg in 72 hrs</td>
<td>1</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Moxonidine (Nizoral)</td>
<td>25 mg/ml</td>
<td>5</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Midazolam (Hypnovel)</td>
<td>10 mg/2 ml</td>
<td>10</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Metoclopramide</td>
<td>10 mg/ml</td>
<td>3</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Sodium Chloride 0.9%</td>
<td>10 ml</td>
<td>10</td>
<td>To be given as directed</td>
<td></td>
</tr>
<tr>
<td>Water for Injection</td>
<td>15 ml</td>
<td>10</td>
<td>To be given as directed</td>
<td></td>
</tr>
</tbody>
</table>

For legal purposes Diamorphine must be prescribed in the doctor's own handwriting. Please copy the information into the space available under each entry for diamorphine and prescribe the dose range for the patient.

<table>
<thead>
<tr>
<th>Diamorphine injection</th>
<th>10 mg ampoule</th>
<th>80 mg, 10 mg minims</th>
<th>Dose range and directions</th>
</tr>
</thead>
</table>
| Diamorphine injection | 30 mg ampoule  | 165 mg one hour and 5 mg minims | Dose range and directions |}

Issue box to Macmillan nurse specialist (Name): ................................................................. Date: .................................................................

DOCTORS SIGNATURE: ................................................................. Date: .................................................................
Dispensing Pharmacist signature: ................................................................. Date: .................................................................
Macmillan nurse receipt signature: ................................................................. Date: .................................................................

Completed prescription to be kept in Pharmacy, one copy to be placed in the palliative care box to be retained by Macmillan nurse on completion of use.
Project development: 1st Audit

- Audit after 24 boxes used
- Outcomes
  - Boxes increased to 7
  - Modifications made to the release prescription to clarify controlled drug prescription
  - Stock control sheet added for controlled drugs
  - Documentation amended for syringe driver contents
  - All pharmacists trained to dispense to address problems of out of hours prescription
  - Levomepromazine ampoules increased to 5
  - Metoclopramide added
  - Cost of drugs £112.23
- Need for specific symptom care guidelines identified
Retrospective review 2001-09

- **Methods:** Retrospective review of the palliative care drug box prescriptions, medication use and outcomes during the period July 2001 to July 2009.

- All children who had 1 or more boxes prescribed identified through team records and palliative care records to identify:
  - Age, demographic and diagnostic details
  - Drug box documentation reviewed to identify:
    - Details of each prescription
    - Whether box was dispensed,
    - Details of drugs administered
    - Outcomes in terms of symptom management and adverse effects
Audit Outcomes

Prescribing and using the boxes
- 95 boxes were prescribed for 90 children:
  - 64 with cancer and 26 with other life limiting conditions.
  - 37 intravenous (IV) and 49 subcutaneous (SC)
- Two children each had 3 box prescriptions at different times reflecting difficulty in identifying end of life.
- Twenty nine palliative care drug box prescriptions were not used (30%)
  - (10 oncology and 19 non oncology).
  - 10 of this group moved from home to hospice for end of life care
Audit Outcomes: Contents of the syringe driver (1)

- 92 infusions were commenced via Graseby MS26 syringe driver (McKinley T34 from 2009)
- Most common combinations were:
  - diamorphine, midazolam & levomepromazine (N=15)
  - diamorphine & midazolam (N=13)
  - diamorphine, midazolam & cyclizine (N=12);
  - diamorphine & cyclizine (N=9).
Audit Outcomes: Contents of the syringe driver (2)

- Contents of syringe renewed every 24 hours and continued for a median of 75 hours (range 1 hour to 912 hours).
- >Fifty percent of drug combinations were commenced / finished, or the dose changed outside normal working hours.
- No adverse effects reported other than a possible acute dystonic reaction associated with an IV bolus of cyclizine to control nausea and vomiting.
- Hyoscine Hydrobromide administered by a transdermal patch and/or SC bolus.
6 essential drugs to control 78% of symptoms

- Seventy eight percent of symptoms were controlled with a combination of one or more of the following:
  - a strong opiate, (morphine or diamorphine) cyclizine, haloperidol, levomepromazine, midazolam and hyoscine hydrobromide
  - Where medication other than these 6 “essential drugs” was required to control symptoms this had usually been started before end of life care.
Other drugs used

- Alfentanil
- Oxycodone
- Clonazepam
- Ketamine
- Dexmethasone
- Hyoscine Butylbromide
## Drugs and doses given by CSCI/ CIVI

<table>
<thead>
<tr>
<th>Drug</th>
<th>Median starting dose mg/kg/24</th>
<th>Median final dose mg/kg/24</th>
<th>N = the no times the drug used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclizine</td>
<td>2.1</td>
<td>2.3</td>
<td>22</td>
</tr>
<tr>
<td>Diamorphine</td>
<td>0.7</td>
<td>1</td>
<td>48</td>
</tr>
<tr>
<td>Haloperidol</td>
<td>0.04</td>
<td>0.06</td>
<td>15</td>
</tr>
<tr>
<td>Hysocine Hydrobromide</td>
<td>0.03</td>
<td>0.03</td>
<td>12</td>
</tr>
<tr>
<td>Levomepromazine</td>
<td>0.3</td>
<td>0.4</td>
<td>26</td>
</tr>
<tr>
<td>Midazolam</td>
<td>0.3</td>
<td>0.5</td>
<td>48</td>
</tr>
</tbody>
</table>
Safety of controlled drugs in the home

- Drug boxes remained in the house a median of 8 days (range <1 to 145 days).
- Despite several families with known substance abusers, all medication was accounted for, except one instance when the morphine “disappeared” from the unused box after the child’s death. (rapid discharge family not previously known to SPCT)
Haloperidol and Levomepromazine:

- Although use of haloperidol or levomepromazine is widespread in paediatric palliative care in the UK (Goldman et al 2006)
- Evidence for their safety, efficacy and appropriate doses in children anecdotal.
- This audit provides the first hard data about the appropriate doses of these 2 drugs and their efficacy in dying children in all routes
- Fewer children had refractory nausea and vomiting with levomepromazine than with cyclizine, haloperidol or a combination of both (Brook et al in press).
- Levomepromazine utilised more frequently in last 2 years
Discussion

- Although concept of ‘just in case palliative care drug boxes’ has been advocated as best practice in adult palliative care
- No clear consensus as to which drugs these boxes should contain,
- This is the 1st report to evaluate the efficacy of palliative care drug boxes, including the drugs and doses actually used for symptom management in home based end of life care for children
Next Steps

- Drug box contents being reviewed and reduced to 6 essential drugs
  - Emergency drugs removed (except dexamethasone)
  - Cost of drugs < £80
  - Ambulatory pumps changed to McKinley T34 for safety and clinical governance
  - All documentation being reviewed and rewritten
  - Need to take account of recent legislation post Shipman
  - Need to ensure clear audit trail for prescribing, dispensing utilisation and destruction / return of controlled drugs

- Buccal Midazolam prescribed for emergency management of seizures and acute agitation

- Need to take account of alternative routes for the management of breakthrough pain e.g. buccal, SL intranasal
  - May reduce need for parental analgesia
Next Steps

- Symptom care guidelines complete
- Care of the dying child pathway being piloted
- Pro-active audit of palliative care drug boxes and end of life symptom management for children and young people.
Thank you
Any Questions???
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